

LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM

Task Force on Transitional Services and Supports

March 1, 2007

The Task Force convened three meetings on December 8, 2006 as well as January 11 and February 1, 2007 in San Leandro, Los Angeles and Sacramento. The Chair of the Task Force, Mr. Dave Kears, and the Vice-Chair, Mr. Rick Rollens, conducted the meetings with the staff assistance of Sue North, the Commission's Executive Director. The Task Force focused first on identifying the most compelling policy problems associated with the range of issues facing persons with autism and ASD who are aging out of the school system and over the course of their adult lives. At the second meeting the task force refined the problem statement and began to identify potential recommendation to address each of the issues. At the third and final meeting the task force developed recommendations as well as narrowed the scope to focus on a high priority practical set of recommendations to present to the Commission.

Overview

California is experiencing a massive increase in persons with diagnosed autism in both the regional centers and the schools. This "tsunami wave" needs to be recognized and policies and programs need to be reformulated to address this population as it ages into adulthood beginning in the next three to five years.

Presently, the state's systems for adults with disabilities have not been designed to serve persons with autism. Persons with ASD will likely also create new demands for public services in California including employment, adult education, supportive housing and self directed services. Every major initiative that is intended to address unmet needs in California (e.g., housing bond funds, Proposition 63 mental health funding, etc.) needs to be reviewed with an eye towards advocacy to assure persons with ASD have full access and integration into various community improvements.

If the state does nothing, these populations will likely repeat the tragic history of the seriously mentally ill after deinstitutionalization in California. Persons with ASD will be "served" by a public response one way or another—humane policies and informed programs or by poverty, homelessness and a dehumanizing criminal justice system.

Persons with ASD transitioning into adulthood need a 'life plan'—their educational, social, residential and employment supports need to be developed with the person, family, friends and community supporters. In the existing system, the range of persons with ASD are not all eligible as a diagnostic group, those not eligible for regional center of special education services will nonetheless turn to other existing state systems such as

higher education, rehabilitation, mental health and employment agencies. These systems also need adaptation to better serve this population.

Further, many state service programs for the disabled respond to crises when maintenance of functional level is often a critical goal. Services should not be predicated on a punitive model—offered only in response to a crisis. State and local partnerships in policies and programs; public-private partnerships and programs; personalized planning based on the person's strengths ("gift-based, not disability-based assessments and planning which assumes competence")—all need to be done in the context of interagency collaboration and cooperation involving all the relevant agencies of government.

A few other items of total consensus which the task force urges strong support from the Commission are culturally competent, individualized policies and services for this population at any age. Moreover, families and communities need accessible information and systems of care. The state needs to assure better understanding by the public and agencies in the broader community about ASD. And all those who offer services from paraprofessionals to clinicians need specific training in the particular challenges presented by persons with ASD. This is a unique population with high sensory sensitivity, behavioral needs and special gifts. They are not a "problem" to society, they offer society unique gifts if we are able to receive them.

The following offers the priority problems and preliminary recommendations from the Task Force on Transitional Services and Supports:

I. Priority One: Housing

Among the special needs populations of the state, persons with ASD represent a growing group emerging into adulthood which will need new options in supportive housing arrangements in our communities. Since it takes years to bring housing developments from planning to occupancy, the time to invest in this need is now. We know that over 30,000 persons with autism will be looking for living arrangements in the next few years. We need to expressly include design, planning and development for these supportive housing arrangements. Since any housing requires a significant investment to achieve even a modest increase in available housing, particular emphasis needs to be placed on this need in order to assure future progress. There is a need for educating families and persons with ASD on housing options and to develop a continuum based on individual abilities and family circumstance. For those families with means, as an example, state policy ought to encourage family cooperatives to support the development of specialized housing.

Preliminary Recommendations:

The housing elements of local governments need to explicitly include persons with ASD—they need inclusion into safe and secure community systems of care which included supportive housing.

California needs to allow for the creation of public/private trust funds and other state financing incentives. There is a particular need for transitional housing for adolescents into adulthood and independent living services for ASD.

Any housing bond funds directed towards persons with disabilities needs to explicitly include ASD persons.

Work Plan/Staff Recommendations:

Data/Information:

Develop inventory of programs to be reviewed in depth

Collect data

Review any data related to regional and age distribution of ASD persons

Establish a ASD housing timetable--how many persons aging out in 3, 4, 5 years

Experts/Research review:

Identify leading experts in California on supportive housing (e.g., regional centers, mental health, state housing finance, etc.)

Convene working group pf experts willing to review materials/ comment/ collaborate on specific solutions

Models:

Pick the best two or three models based on regional (e.g., urban, suburban, rural) variation for short (immediate, 2-3 year and 3 + year initiative opportunities

Timelines/Analysis:

Identify existing Housing element requirements as it relates to special populations

Summarize specific models of supportive housing in California

Detail specific correlations for program/collaboration requirements, costs, and timelines

Feasibility Projects:

Identify "sure bet opportunities" with existing housing programs, funding cycles

Prepare recommendations regarding mid and longer range projects offering promise

Fiscal Analysis:

Establish an estimate of existing public investments in supportive housing (e.g., all sources of funds whenever possible)

Establish estimates for cost per unit regionally

Develop a fiscal estimate: overall need funding vs. cost per unit including potential cost efficiencies based on the scale of the project

Estimate sustained state administrative costs over time

Legislative Solution Development:

Draft package of legislation to reflect recommendations

Vet drafts with administrative agencies, legislative staff, and core experts

Offer a priority list for Commission's consideration

II. Priority Two: Life Skills /Vocational Pathways

Existing systems were not designed to serve the ASD population. As a result, there is a dearth of training and professional development, successful program models in vocational and adult education, and the full range of higher education systems (e.g., community college, state universities and the University of California) as it relates to persons with ASD.

Those few programs that do exist in higher education for persons with disabilities focus largely on those with physical limitations. Persons with Aspergers' Syndrome, as an example, frequently have high cognitive functioning but too often also have profound behavioral and socialization barriers that dramatically limit their ability to succeed in college. Yet they have great potential for making a significant contribution in terms of potential careers. The predominant model of vocational training is grounded in English only, lacks flexibility and is not sustainable over a lifetime for too many people with this range of disabilities.

The scope of services needed for this population is very broad due to the eclectic nature of autism. There is a real need for developing models for how to test skills and talents, how to assess strengths as well as weaknesses on an individualized basis. There is also a

need for developing models for training and supportive employment for the same reason—this population represents a broad spectrum of people that, if served, could develop into a special talent pool for the state.

Preliminary Recommendations:

Expand high school options (more than one possible track in Spec Ed)—e.g., ability to access vocational classes while on an academic track and vice-versa. Engage community colleges to design flexible transition programs in partnership with schools. Create life skills/academics./ vocational tracks for special needs ASD young adults to get a skill assessment, career counseling leading to diplomas, certificates and other demonstrations of competency. Include transitional experiences, specialized mentoring, job placement and coaching in new models for success.

Business incentives need to be permanent—they take too much time and money investment to move a workplace towards inclusion of persons w/ special needs

Expand job types in traditional systems such as regional centers and rehabilitation programs. Design new ways to assess skills and to fit the job and job supports to the person emphasizing success, not just crisis intervention.

Work Plan/Staff Recommendations:

Data/Information:

Prepare an estimate of ASD children and their "aging out" profile in terms of K-12 over the next decade

Review service need and utilization data about higher ed/employment and training/transitions into adulthood pattern for general populace/ special needs populations/prepare ASD estimate

Gather data regarding cost/benefits of various skill assessment/career planning services/activities

Experts/Research review:

Develop a core work group of education. Employment and training and special needs support services experts

Review research identified by the group

Models:

Create at least one "focus group" of young ASD adults to review and comment on models for transition supports

Timelines/Analysis:

Establish short, mid- and long term goals for program development

Feasibility Projects:

Look for "willing participants"(e.g., educational institutions, employers, regional centers) willing to experiment (as evidenced by local resource opportunities they are prepared to invest)

Determine what resources they are missing (e.g., specific types of funding, evaluation, etc.)

Fiscal Analysis:

Determine the approximate cost of program expansion, new program development--overall costs plus cost per person served correlated to recommended program type

Prepare a set of recommendations for the Commission regarding the potential scope of program development

Legislative Solution Development:

Prepare draft legislation to reflect recommendations

Priority Three: Personal Safety and the Criminal Justice System

There are already reports of tragic incidents involving young teens and even children with ASD when local police completely misconstrue ASD behavior and the incident results in real harm. We already know about the human costs of the state's criminalization of the mentally ill. We do NOT want the state to repeat the same mistakes of public policy and neglect as seen in our mental health system over the past forty years! We need to initiate methods and policies to identify and divert ASD persons from the criminal justice system whenever possible. We need to assure the personnel in our criminal justice system have adequate training and skills to respond appropriately to ASD persons in the community.

In addition, the behavioral attributes of many persons with ASD make them vulnerable to misunderstanding in our criminal justice system. Like too many other persons with

disabilities, they are personally vulnerable to those who would victimize. Not only are persons with ASD at risk for physical, emotional and sexual abuse, but special training and protocols need to be developed and conducted when allegations of abuse are made. The court system needs a degree of specialized training to assure access to the justice for this population.

Preliminary recommendations:

Mandate training for all first responders, especially the police to insure improved management of persons with ASD in the community

Assure training for school, mental health and court personnel regarding the behavioral manifestations of persons with ASD and providing successful skill development to assure better communication and understanding.

Design risk reduction and victimization training for persons with ASD so they can know and understand their rights, and know how to seek help when they need it from the court system.

Work Plan/Staff Recommendations:

Data/Information:

Search for any relevant statistics regarding crimes involving ASD persons in California

Review various estimates and other data offered as "evidence"

Gather data regarding the "payoff" of training first responders--what outcomes might we expect if we did what

Experts/Research review:

Engage law enforcement, training, disability rights advocates and enlist them as advisors

Models:

Review the existing models the state uses for training law enforcement, paraprofessionals and professionals in various systems of care

Review how schools and regional centers deal with these issues now

Timelines/Analysis:

Prepare estimate of time need to accomplish which results

Feasibility Projects:

Analyze whether we know what to do but just have not done it vs. we are not sure what works

Is there a need for testing new methods/ refining existing methods for this population or shall we "roll out" a simple strategic plan for implementation

Fiscal Analysis:

How much will it cost to fully integrate these activities into the existing systems

Options for implementation and incremental solutions over time

Legislative Solution Development:

Prepare draft language to reflect recommendation choices

Priority Four: Medical Care Policy Issues

This population is unlike other generations before it in that so many more persons are being diagnosed today with ASD, especially in early childhood. As such, they are subjected to a wide range of medical treatment interventions, most of which have not been monitored before over a lifetime. Medical review, efficacy of early intervention techniques vs. other interventions in adolescence and adulthood, monitoring comorbid conditions along with adolescent development in a world that intervenes largely based on behavior---this population needs some special oversight in terms of the appropriateness, effectiveness and cumulative consequences of long term treatment and behavioral interventions.

This population has major access problems to primary care and dental care—providers need specialized training. The rates paid for treating these populations need to reflect that practitioners may often need to spend more time per visit than they do with other patients.

Preliminary Recommendations:

Establish a method (e.g., registry, research protocols, etc.) to monitor over the long term the treatment interventions used with the ASD population. Evaluate the efficacy of various treatments such as medications, behavioral interventions, etc to identify and address any specific risks that might be present.

Rate differentials, especially in programs such as Medi-Cal need to be adopted to serve persons with ASD.

Regional Centers need medical coordinators, especially for assisting in accessing dental care, for persons with ASD.

Provide incentives for health professionals to receive training in serving the ASD population (e.g., loan forgiveness, grants, scholarships, etc.)

Work Plan/Staff Recommendations:

Data/Information:

Review any co morbidity data for ASD populations

Review prevalence of iatrogenic risks associated with special need populations

Review regional center data for whenever information is gather relevant to this topic for the DD population as a whole

Experts/Research review:

Identify experts in primary care, dental care, risk assessment and quality assurance mechanisms, especially if they have expertise in ASD or other special needs groups

Enlist their help in reviewing/commenting on issues/recommendations

Models:

Review medical team models (e.g., institution and community based) to establish the elements of medical participation and functions needed

Prepare a set of possible models (e.g., primary, secondary, tertiary systems of care/ integrated managed care vs. specialized systems of care)

Timelines/Analysis:

Develop a timeline for implementing specific proposals designed to integrate medical policy reviews into existing systems of care

Feasibility Projects:

Determine if there is a need to test programs/policies designed to review medical policy issues

Prepare a feasibility analysis if needed

Fiscal Analysis:

Determine costs for adequate medical monitoring based on mental health system and regional center systems and private quality assurance systems

Extrapolate a cost estimate for implementing such a system in California

Legislative Solution Development:

Develop proposed language to reflect recommendations